

Surviving Adolescence

by *Lisbeth Krawiecki*, LMSW, ACSW

If you are the parent of a teenager with special needs and do not know what to expect, do not worry, you are not alone. Parents ask for guidance during the "terrible twos" and during teen years more than at any other developmental stage. During both of these stages, kids are seeking out autonomy and independence and finding measures of control over their environment. At the same time, they need support and nurturing. Their job is to test their limits-and they will! Adolescents are going through physiological changes as well as emotional and developmental changes. Their bodies are changing and developing- perhaps not in the ways they thought. It is during this stage that teens begin to form identification with peers, start to question beliefs and values, and sort out their own identities and future goals. When we look at how we can foster a sense of competence in our children, we need to look at issues of self-acceptance, social inclusion, and autonomy.

What are we really dealing with?

All of this may not happen easily, even for a "typical" teen. Parents will need to keep a few things in mind in order to survive adolescence. Your kids may have differences, but they are probably more like their peers than not. So, first make sure you are dealing with the real issue. It is human nature for a parent to blame the disability. Kids with shunts get headaches, and it is not always a shunt malfunction. Deciphering the real issue may not always be easy!

Do not assume that your child has the same feelings you do. You bring with you the history of your own teen years and what your dreams are for your child. He has grown up with his differences, and may not have the thoughts or feelings you perceive. Part of being a teenager is learning who you are-physically and emotionally. Living with his disability since birth does not mean he understands the true nature of it or what the future holds for him. Teens who have physical disabilities may have feelings about the "intactness" of their bodies. This is a good time to explain, or re-explain if told before, the nature of his disability. Tell him as much as he can understand, and invite him to ask questions.

Allow your teen to make choices

Many teens have questions and fears about their future. It is important to their self-esteem to understand and learn coping mechanisms to keep a disability from becoming a handicap. Part of your teen's coping abilities will depend on how "normalized" her life can be. Be aware of the obstacles your child may face and help her to make choices. Despite lack of language or independent movement, any child can make some sort of choice. Teens need to be allowed to make choices so they may feel somewhat in control of their lives. We forget how many choices we make for our kids with special needs. There are many choices we cannot let our kids make. They have to go to therapy, take certain medications, allow a caregiver to bathe them, etc. So, seek out situations in which

they can make choices. If your child chooses to dye her hair green, this may be the only realistic choice of expression she can make for herself.

How can we help our kids fit in?

Part of the nature of adolescence is the need to "fit in" and not be different. Your kids do have differences, and they live with them every day. They need to be given as many opportunities as possible to feel "the same," and to engage in typical teen activities like going to the prom or getting a driver's license. There are many programs available to assist young people who have special needs with social and recreational activities. Get your teenager involved and talk to him about what he wants to do. Remember, some kids are social butterflies and some are loners, whether or not they have special needs. So be careful not to push them into relationships and social situations they are not interested in.

There are some creative ways to attract peers. Canine Companions for Independence (an organization which provides service dogs for people who have disabilities) is a wonderful way of supporting your child's independence. Dogs are a natural magnet, and often attract people and invite questions and conversation. We cannot make friends for our kids, but we can invite situations which will promote these possibilities.

Pick your battles!!

It is easy to stay in continual conflict with a teenager. Let him win the unimportant battles, but set firm limits. Parents of children with special needs often take on too many roles-that of therapist, nurse, and friend. Some of you may not have choices, but whenever possible, be a parent first. Set limits for your child, and have expectations of him. Ensure that there are consequences when rules have been broken or limits pushed. One of the most difficult things for parents to do is to have their teen learn from natural consequences, at times allowing them to fail. We have to remember that we all learn from our mistakes, and our kids should be given that opportunity as well.

Teach your kids to be proud

Give your kids responsibilities for themselves and for the household. We all know it is easier and faster to do certain things ourselves, but a major part of helping our kids become self-competent and helping ourselves stay sane later on will be to teach them to be as independent as possible. Let them feel proud of their accomplishments, no matter how small and insignificant they may seem to you. Help your teen practice how to feel proud about who she is. Help her practice how to explain her disability to others if she chooses to do so. Help her with a repertoire of "come backs" for those unwanted questions or unkind comments. Focusing on strengths can help us cope.

More than the birds and bees!

As parents of teens who have special needs, you too will need to learn coping strategies to meet the challenges that you face. One of the hardest challenges to deal with is that your teen is a sexual being, and part of your ability to survive will depend on acknowledging this. Your child may be a 6-year-old developmentally, but her body will most likely mature at an age-appropriate level. "Typical" kids can learn about maturation, sexually appropriate behaviors and sexual activities incidentally, through everyday

activities and social situations, as well as from their parents. As the parents of a child who has special needs, your job as "sex educator" has more responsibility.

Talk to your teen regularly and repetitively about the changes that are going on in her body. Teens need to be taught socially appropriate ways of handling some of their sexual feelings, and they need education about personal safety. If your belief system allows for it, they need the opportunity to have privacy for masturbation, and need to be taught when and where this is appropriate. If you are the parent of a child who has a physical disability, and who requires personal assistance for self-care, you and your child may begin to feel uncomfortable with this situation as maturation begins. If possible, look into using a same-sex care provider. Your teen may have questions about sexual performance and reproduction. If you feel uncomfortable, it is perfectly okay to seek outside help in discussing these issues. You may want to schedule an appointment for your teen to talk with her physician or a counselor who has experience in explaining these physiological issues.

Give yourself permission

Your kids may require adult assistance at all times. Seek out other parents, pair your kids up, and share caretaking responsibilities. Give yourself permission to take a few hours for yourself. Use respite. Your kids need time away from you as much as you may need time away from them!! Kids with disabilities do not often have the luxury of privacy, so they may need their privacy re-defined as time away from their primary caretaker.

Around the time of adolescence, parents often have a recurrence of grief and the need to once again learn acceptance. [It is often a time when they realize that their child's disability will always be with them.] Their child who has a disability will become an adult who has a disability. Prepare yourselves, gather supports, and you and your teen will survive adolescence! EP

Resources

American Association of Adapted Sport Programs
Bev Vaughn, President and Founder
PO Box 538
Pine Lake, GA 30072
(404) 294-0070
Web site: <http://www.aaasp.org>

Canine Companions for Independence
National Headquarters
PO Box 446
Santa Rosa, CA 95402-0446
(800) 572-2275 V/TDD

Lisbeth Krawiecki, LMSW, ACSW, is a Social Worker at Egleston Scottish Rite Rehabilitation in Atlanta, GA, and works in private practice mainly with children who have special needs and their families. She serves on the board of FOCUS, Families of Children Under Stress, an organization in Atlanta offering support and resources to

families of children with special needs. Ms. Krawiecki has survived adolescence three times, from the parent's perspective, and now enjoys the company of her grown children.

Reproduced with permission from:

Exceptional Parent
555 Kinderkamack Road
Oradell, NJ 07649-1517
Tel: (201) 634-6550
Fax: (201) 634-6599
Web: www.eparent.com